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Getting to "No" You:

When Nonspeaking Autistic People Refuse Music Therapy

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Abstract

Nonspeaking autistic people[1] frequently begin music therapy at the request of others. Typically, family or care systems are tasked with making decisions on their behalf and have decided this service will be of benefit. Consequently, music therapy is a given rather than a choice. For this paper I have used my own evolving understanding to explore the complexities and power dynamics related to nonspeaking people being able to say "no" to music therapy. Elements in this discussion include: (a) the ability, and safety, to say "no" in the context of a culture of compliance, (b) the complicated relationship between music therapists and the systems within which they work, and how this affects the therapy relationship, and (c) the role of music therapy practice standards. I advocate the following: (1) presume competence, (2) enter the therapy space with curiosity and openness, (3) be willing to "get to know," (4) coping skills or communication attempts are not "behavior" in need of correction, and (5) learn how each nonspeaking person communicates "no." Actively encouraging and respecting treatment refusal goes a long way toward building a respectful music therapy practice/relationship.

Keywords: nonspeaking autistic; intellectual disability; culture of compliance; self-determination; refusing music therapy

How do Nonspeaking People Arrive in Music Therapy?

As a person who is highly verbal, it took me a long time to figure out how to be a better listener to nonspeaking people. I spent two-thirds of my life working as a music therapist and staff member in a state institution[2] for adults with labels of "intellectual and developmental disabilities." The vast majority of the people I worked with were nonspeaking, and, just as many, autistic. It is from this perspective that I explore the complexities and power dynamics related to nonspeaking people being able to say "no" to

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music therapy.

When I was hired to work in the institution I inherited the caseload of the music therapist who was there before me. Although there were case reports and objectives, it was often difficult to discern how people had initially come to take part in music therapy. Music therapists are trained to address feelings related to termination as well as preparing people for transitions; however, we don't necessarily have conversations with nonspeaking disabled people about whether or not they want a new music therapist or if they even wish to *receive* music therapy.

Naturally, my music therapy caseload evolved over the years. Usually I would see new people when a member of the care team asked me if I might add a particular person to a music therapy group — more often than not because “s/he/they like music” or they "don't take part in many other activities.” Another periodic source of referrals was family members (parents, usually, but sometimes siblings) who would ask if their loved one could take part in “some sort of music activity.”

There were also times when I would observe someone in one of the units and wonder if they might benefit from music therapy, effectively acting as my own referral source. Rather than assuming people wanted to be in music therapy, I explained who I was, what I did, and why I was approaching them. I then left it up to the individual to find a way to connect with me if they were interested in trying music therapy. Since most of the people I worked with were nonspeaking, I checked in with them periodically in case they were having a hard time initiating contact. This is an important step in supporting self-determination.

How Nonspeaking People say No

Over the years I discovered many of the nuanced ways nonspeaking people communicate “no.” Sometimes it was as blunt as packing up my guitar mid-session and handing me the case. One man would take my hand and pull me to the door. Then he would run back to lie down on the couch, looking back toward me to make sure I got the message. It could be not getting up when the person customarily jumped up to go with me, or making sure to be “asleep” when I arrived.

Dave[3] used to escort me to the door of the unit, let my arm go, and wait for me to leave, watching me until I walked back out through the front door. Only then would he turn around and move along, back to his routine. Nancy stoutly refused to go into the music room with me. She would turn her wheelchair around, grab my hand, and bring me outside to take her for a walk. She was quite capable of asserting herself and letting me know what she needed, and she was just as clear that she had no intention of letting me go. When a nonspeaking person feels heard, they can be highly effective communicators.

For the longest time Seema stood up to indicate “yes” when I asked her if she wanted to go to music therapy. Even when she appeared distressed some days, she continued to stand up when I approached her with an invitation to join me. At some point, this shifted. I noticed she was standing up less often or she seemed reticent. I wasn't sure whether she was telling me she no longer wanted to come to music therapy or if she wasn't feeling well. I tried asking her if she would prefer to go for a walk instead, and she usually agreed to that. Eventually, she simply stopped getting up. I spoke with her, and I asked her if she felt she no longer needed music therapy, and, if so, would she mind coming with me for one more session. That way we could say goodbye to each other and honor the work we had done together. She agreed, and she came for one last session.

Sometimes “no” is communicated in profoundly ambivalent ways. Thomas took this to an extreme. Such was his state of ambivalence, that, for months, he literally stood in the doorway, holding on to my hand, refusing to move forward to go with me, and also refusing to move backward and letting me go. I found it was usually easier for me to hear people say “no” to me than it was for the support staff in the units. Once they finally got used to the idea that saying "no" to music therapy was indeed okay, there were some who seemed to feel badly for me, concerned I would feel rejected. I reassured the person refusing music therapy that saying "no" to me was a good thing. It told me they trusted our relationship, they knew what they needed in that moment, and they had communicated their decision in the most effective way they could. There were, of course, times I needed to address my countertransference feelings in supervision. This happened more often when I didn't realize I was being told "no," or "I would like to stop receiving music therapy now."

A frequent reason for not getting up to go with me, however, was because the person had difficulty communicating a different issue. For example, sometimes people needed assistance with toileting. Or they had an injury or some sort of pain requiring medical attention, and nobody had discovered it yet. Or they might be waiting for someone who told them they were going for an outing. Sometimes "no" had nothing to do with music therapy, and there were often times when I misinterpreted people's seeming non-response.

Do Autistic People Need Therapy?

Being autistic, especially nonspeaking and autistic, tends to presuppose the need for therapy or "treatment,"[4] often designed to address, or more accurately, diminish (or "mask") traits which are perceived as "characteristic" of autism. Walker (2021) and many other autistic scholars, have challenged what they describe as the "pathology paradigm" (Kupferstein, 2020; Milton, 2012; O'Dell et al., 2016). The premise is that it bases its understanding of autistic people on the assumption that there is a standard, or "normal," way to be and present oneself. Within this type of framework, autistic people are perceived as deficient and in need of remediation. Instead, autistic scholars advocate valuing neurodiversity, liberating the notion there is one "correct" version of human neurology and variety (Walker, 2021, pp. 13-16).

Many nonspeaking autistic people are presumed to be intellectually disabled, and labeled as such, because of a lack of speech. Further, a tendency to frame much of what nonspeaking autistic people do as "behavior" sets the scene for a lifetime of "therapy." There are, however, numerous examples over the last three decades of nonspeaking people demonstrating communicative and intellectual competence, either when provided with access to alternative communication means or when nonverbal expressions are respected (Baggs, 2013; Communication First, 2021; O'Neill, 1999; Savarese, 2009; Sequenzia, 2019). In spite of strong advocacy within the disability rights community to move toward models which embrace and accept neurodivergent perspectives, most schools, healthcare, and institutional systems continue to rely on outdated deficit-based paradigms and therapies.

For example, the vast majority of current autism services in the United States rely heavily on approaches which focus on behavioral change, most notably Applied Behavioral Analysis (ABA). ABA, however, has been challenged by many autistic advocacy groups as problematic in that its objective is "making an autistic child look and act non-autistic" (Autistic Self Advocacy Network, 2022; p. 1). Additionally, various authors and researchers have challenged the ethics of this approach citing the ways it impinges on autistic autonomy (Wilkenfeld & McCarthy, 2020) and raising concerns related to the potential for iatrogenic effects (Kupferstein, 2018, 2019; McGill & Robinson, 2021).

Inherent in music therapy training is the intention to support the process of choice-making as well as the expression of preferences: choose your sound, choose how you present that sound, choose to be silent, choose to listen, choose when the music starts, and when it stops. Participants also make non-musical choices. For example a person can choose whether they sit on a chair or stand during music therapy, or where in the room they choose to be in relation to the group circle, or how they position themselves in relation to the therapist. But what happens if the choice is "no"? As in, "No thanks, I don't want to come to music therapy"?

Music therapists don't seem to talk about treatment refusal. The dearth of literature related to refusing, or declining, music therapy may be because, as a profession, we have had to continuously advocate and assert our position within the larger healthcare system (American Music Therapy Association, 2021). Thus, music therapy finds itself in the uncomfortable position of needing to have the support of broader systems of care within society. Not only does this grant us access to those who may benefit from our services, it also presents opportunities for remuneration. However, by choosing this path, we simultaneously risk alienating disabled service users, who may have their own complicated relationships with these systems (Kelly & Chapman, 2015).

Most music therapists[5] have been taught models of "treating" autism. These include biomedical, behavioral/skills-based, and/or developmental approaches found outside of music therapy, demonstrating our professional tendency to work within existing "treatment" frameworks. Even improvisational models have alleviation of autistic "symptoms" as their ultimate goal. In each of these frameworks there is an "unquestioned premise that responsibility for change lies ultimately with the disabled person, and that the disabled person will benefit from this change" (Cameron, 2014; The Medical Model section, para. 7). Music therapists need to question the basis of models that use assessments which locate "presenting problems" within the autistic individual.

Beebe (2020) surveyed music therapists with regard to their attitudes toward self-determination for people with diagnoses of intellectual disabilities. Most music therapists described ways of incorporating self-determination in sessions as: offering choices of instruments and activities/interventions and also by following the client's lead in terms of how the session and the therapy plays out (p. 54). There was, however, no reference as to whether or not disabled people could convey their wish for self-determination by refusing to attend music therapy. From my perspective, following a client's lead is the work of therapy, part of building the therapy relationship. Unless it is done with specific intention, it will not necessarily help someone work toward self-determination.

Saying "No" within a Culture of Compliance

My experiences in school, in practicums, and in my internship, as well as having spent my first year at the institution in the Music Room, taught me to believe people usually *want* to be in music therapy. When I started to work in the residential units however, I found, in fact, many people expressed a decided lack of enthusiasm when I invited them to sessions. I wasn't sure what to do. Music therapy was supposed to be miraculous. Where every other therapeutic approach may fail, "music therapy wins!" Young Edward screamed his way through much of his first session with Paul Nordoff and Clive Robbins. Obviously, he recognized this was something *different*, and he began to play with them musically before his time was even up for the day.

I was still new to music therapy, though, and I saw refusal, not only as something of a personal failure, but, perhaps more so, a problem with the person who was not interested. At first, I thought, "People with disabilities don't refuse music therapy." Music therapists have a general understanding that "no" is simply something to address in the music. But I was not going to be able to address anything if the person did not show up for their session. So when people did not seem to want to come to music therapy, I felt it was my job to do what I could to get that person to their session, so we could *work* with that "no!" And if *I* didn't have any luck convincing them, their direct support staff certainly would. Eventually, I learned I needed to be more present to my *clients* than to music therapy.

There is, however, also a complicated relationship between music therapists and the facilities/systems within which they work, and this, too, affects the therapy relationship.

> Professionals, as adversarial allies to service users, find ourselves in a predicament; we are challenged to work within an unjust and inadequate system. On the one hand, we are forced to perpetuate injustice by working within the system in order to ensure. . .services are made available to marginalized people. On the other hand, many of us aspire to change the founding structure of this system dramatically and move toward more equitable forms of care and support. (Kelly & Chapman, 2015, p. 63)

Where there are systems, especially institutionalized systems of care, there is the potential for oppression. My friend, Maureen, a psychologist with whom I worked for many years, put it to me succinctly: “We have the keys to our clients’ homes, and they do not.” For me, it was an opportunity to reflect on my power and privilege in relation to people receiving music therapy. I needed to ask myself, what other things I had access to as a person designated as “staff” that people who lived in our facility did not.

But I’m Trying to “Help” You

One troubling expression of power is “hand-over-hand,” a “technique” [6] in which a teacher, therapist, or other designated “staff' person, physically manipulates and guides an individual’s hands in order to complete a particular task or activity. The prevailing notion is that this type of intervention will “help” nonspeaking people — whose responses, or lack of, give the appearance of not knowing or understanding what is being asked of them — to develop the muscle memory needed to learn how to do things like feeding themselves, brushing their teeth, or taking part in activities, like music therapy. This approach is ubiquitous in disability service systems, and, on the surface, it seems to make sense, as most hegemonic beliefs do. As such, I, unquestioningly, fell into the habit of using “hand-over-hand" to “help” people play instruments in music therapy sessions. At the time I was using a skill development model which, in my mind, justified this type of support.

As I began to examine ways I was unconsciously exerting control in sessions, I realized how intrusive a “technique” like “hand-over-hand” could be. After focused research and collaborations with autistic adults, I have come to understand it is painful to someone with sensory sensitivities, and, however unintentional, it may become an invasion of space and privacy by the person experiencing it. Critically, for people who are already vulnerable to abuse, it tells them their body is not theirs to control, that anyone can have access to it, and, worse, that compliance is expected.

I knew I had to change my approach immediately, so I asked support staff to refrain from physically or verbally assisting or intervening with music therapy participants. I asked that they let people interact with the instruments, or not, in whatever way they chose, as long as nobody was getting hurt. Many of my coworkers found this odd, because they were now uncertain as to how they were supposed to be “helping.” Using “hand-over-hand” was such an automatic action on all our parts. It took actual effort to avoid doing it. I explained to my coworkers that we would never know what “our clients” were capable of, or interested in doing musically if we kept jumping in to “help.”

The “helper/helped” dynamic is a powerful one, not just in the relationship between direct support workers and disabled people, but in music therapy as well. After all, how many of us became music therapists so we could “help people?” In their classic paper, *Hell-Bent on Helping: Benevolence, Friendship and the Politics of Help*, Emma Van der Klift and Norman Kunc (1994) note that “professional caretakers are made, not born.” They go on to caution, “Put a third-grade ‘helper’ next to a third-grade ‘helpee’. Add a sizable amount of adult approval, and there you have it…” Most importantly, “We must guard against merely creating another generation of ‘professionals’ and ‘clients’, with the former group seen as perpetually competent, and the latter, perpetually needy” (Friendship and Help section; para. 18).

Practicing within Systemic Limitations

Over the years I have begun to give people a fairly long trial period before I officially include them in my schedule—at least three months of assessment and usually more like a year. This serves a few different purposes: first, it is a way to circumvent the possibility music therapy will immediately become a permanent part of someone's schedule. Most residential or day-based service facilities have to have some kind of schedule which accounts for people's whereabouts during the day. Calling it a "music therapy *trial* period" helps the facility know the person is receiving services, but it may be temporary. Second, it gives the nonspeaking person ample time to decide whether or not they choose to continue receiving this service.

In any context, it takes time to get a sense of who a nonspeaking person is and how they relate to people. During the trial period I encourage participants to help me get to know them through musical and verbal interactions, with the expectation that this will be an interactive dialogue. By the same token, I invite the nonspeaking person to use this time to try and get to know who *I* am and how *I* work, perhaps observing me in different situations. I also try to make a point of acknowledging there may be times when I have to ask people to do something differently because of safety.

During this time we begin to co-create an interactive "dictionary" of sorts. The process is slow, it is repetitive, and inconsistent; however, the intention is clear throughout: "I want to hear what you have to say." We try to figure out either the person's most consistent "yes" or their most consistent "no," while recognizing the potential for mistaken interpretation. I check in frequently, as we go along, to make sure I am "hearing" properly. It is an ongoing process of acknowledging therapeutic ruptures and working together to repair misunderstandings (Eubanks et al., 2018).

One of the biggest challenges for non-autistic clinicians conducting music therapy with nonspeaking autistic people is the enduring sense of uncertainty or not knowing. This uncertainty usually pertains to whether or not we are accurately understanding what the person is trying to communicate. Because of this there is always a risk of projecting our own narratives onto the nonspeaking person.

> When the client has no expressive speech, the therapist is working in the unknown, and in the early stages of my work there was always the uneasy feeling of whether I'd got it right or not. Trusting the gut feeling is a huge learning curve for any therapist while being prepared to acknowledge that one might be wrong. (Warwick, 2019, p. 15)

In spite of our discomfort with not knowing, it is incumbent upon music therapists to continue to encourage nonspeaking autistic people to say "no" and to respect all communicative efforts. With time, as the nonspeaking person begins to trust the therapist to listen, the therapist will simultaneously feel more confident in their ability to hear.

We have little control over the larger systems within which we work and the ways in which these impact the lives of nonspeaking people. We can, however, be mindful and thoughtful in our own interactions. As a profession, we need to become aware of the biases we hold in relation to nonspeaking people. We must rethink what it is we do and how we do it. When we "provide opportunities to make choices"[7] in sessions, we are using a model of therapy in which we are "treating" a perceived inability to make decisions. Instead, we can respect each individual's innate autonomy and embark on a collaborative effort to listen to the choices nonspeaking people are making.

Five Ways to Support Nonspeaking People Respectfully

(1) Presume competence.
  - Immerse yourself in learning about nonspeaking autistic culture.
  - Do not assume a lack of speech indicates a lack of intellectual capacity.
  - Use the principle of the least dangerous assumption, which states: "In the absence of conclusive data…decisions should be based on assumptions which, if incorrect, will have the least dangerous effect on the [individual]" (Donnellan, 1984, p. 142).
  - Assume each nonspeaking person can decide for themselves whether or not they feel music therapy is something that will benefit them.

(2) Enter the therapy space with curiosity and openness.
  - Consider that you may have an idealized image of what you think music therapy should look like.
  - Arrive in sessions with the intention to learn rather than the intention to impose your own ideas.

(3) Be willing to "get to know."
  - Check in regularly with service users. For example, "Let's find a way for you to let me know if there is something we need to stop doing."
  - Engage with and observe nonspeaking music therapy participants, and also be aware of your own reactions and tendencies.

(4) Coping skills or communication attempts are not "behavior" in need of correction.
  - Expecting someone to try and change something that is part of their biological makeup is unethical and is rooted in privilege.
  - Consider that a person's compliance in music therapy may be a coping skill, based on a wish to appease the people who want them to be there.
  - Addressing the after-effects of chronic trauma may be more necessary than getting someone to "act like typically developing peers."
  - Sometimes getting to a point where a nonspeaking person can safely and comfortably refuse music therapy is the work of therapy.

(5) Learn how each nonspeaking person communicates "no."
  - Observe the types of things the nonspeaking person does naturally. These subtle actions may include glances toward you, making a sound, shaking their head, moving closer to you, moving toward the door, taking your hand, pushing you away, and so forth.
  - Use the actions they seem comfortable with to give a specific way to respond to you. For example, "If what I said feels right to you, let me know 'yes' by glancing toward me, or tell me 'no' by looking away (or by making a sound with your voice)."
  - Start with yes/no questions, and then flesh these out by giving the person specific options. You may need to ask, "Would you prefer a different option?"
  - Ask one question at a time, otherwise, it is impossible to know which question the nonspeaking person is responding to.

Conclusion

For many nonspeaking autistic adults, the ability to refuse, effectively saying "no" to music therapy services, is complicated by a number of factors, not the least of which is the assumption they need, or will want, to receive music therapy. A second challenge is knowing whether or not the individual feels safe or comfortable enough to decline, given the expectations, perceptions and power dynamics present in their living situation. An additional obstacle may be our own tendency to idealize music therapy.

Self-determination and self-advocacy are important issues that should be discussed explicitly with nonspeaking autistic people. Essentially, getting to "no" requires a commitment on the part of the music therapist to do the slow, difficult work of figuring out, together with the nonspeaking person, the direction of music therapy and whether or not the service we are offering continues to be relevant in the individual's life.

When we invite nonspeaking people to begin to think about the experience they're having, engage with it, and then decide *for themselves* whether or not it is something they want to continue, we make room for the person's innate self-awareness and self-knowledge while honoring their unique perspectives. If a nonspeaking autistic person decides, in the end, they do want to be in music therapy, then the work can proceed, with both the therapist and service recipient secure in the knowledge they are there because they *want* to be and not because they were simply placed there.

About the Author

Roia recently retired from long-term employment as a music therapist in a residential care facility in the United States. Most of the last 33 years were spent in the company of institutionalized nonspeaking autistic people with whom she collaboratively and continuously worked to evolve into a more respectful music therapist. Her current interests are arts-based research, collage, and reading. Her enduring interests are relationally-based music therapy approaches, reflexive practice and clinical supervision.

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Notes

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[1] In this paper I will be using identity first language, which is generally preferred in the autistic community. For a discussion of this, please see https://autisticadvocacy.org/about-asan/identity-first-language/.

[2] When I refer to “state institutions” I am referring to long-term residential care for people labeled as intellectually disabled which is funded by the government.

[3] All examples are composite sketches of the various ways different individuals have expressed “no.” By choosing to use specific names my hope is that readers will make connections in their own minds to the names of people they have encountered in their music therapy work.

[4] I have intentionally used quotation marks at various points in this paper to encourage readers to consider the language we commonly use, as well as the often unconscious power we wield, when we describe music therapy with nonspeaking autistic people.

[5] This is more the case in the United States. Additionally, I am attempting to highlight the fact that the language we use is based in a medical model understanding of autism, rather than adhering to a social model of disability. This implies autism needs “treatment” for autistic “symptoms” as opposed to using the language of “accommodation” and “coping mechanisms.”

[6] Again, we tend to diminish the effect of potentially intrusive interventions by using professional terms, such as “techniques” and “treatment,” drawing a strong delineation between “staff” and “clients,” and emphasizing the “helpful” nature of our work.

[7] When we say we “provide opportunities to make choices” there’s an implication that we, as music therapists are bestowing the right to make choices on the people receiving services when they have the right to begin with.